

Section I

ASSESSING COMPLEX NEEDS

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Chapter 1

INTRODUCTION

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It is important that everyone understands that people with profound [intellectual and multiple disabilities] have the same rights as every other citizen. We must enable each individual to engage with their world and to achieve their potential so that their lives go beyond being ‘cared for’ to being valued for who they are as people.

(Mencap, 2007, p. 7)

This statement from the Mencap/PMLD Network paper *Meet the People* is an apt introduction to a book that aims to provide insights for those charged with the responsibility of helping people with profound intellectual and multiple disabilities (PMID) to ‘engage with their world’ and ‘achieve their potential’. This is no easy task. However, by taking a thorough, wide-ranging approach that is advocated by this collection of contributors, we hope to instil confidence and motivate the practitioner striving to implement best practice in this field.

In this introductory chapter we explore definitions and causes of intellectual disability and look at some of the key areas that underpin the remaining chapters: the importance of access to health services, the legal and ethical emphasis on mental capacity and the integration of health and social care philosophies.

About whom are we talking?

The current emphasis on person-centredness in services for people with intellectual disabilities can lead to an arguably inappropriate shying away from diagnosis and categorisation. In this book we will argue that on the contrary, clarity and agreement about the use of accurate terminology – specifically here the term profound intellectual and multiple disabilities – is more likely to lead to the development of person-centred action and the implementation of good person-centred approaches (Mansell & Beadle-Brown, 2005).

Defining intellectual disability

The term intellectual disability has been adopted here in recognition of this book’s potentially international readership. In Britain, the term *learning disability* is

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prevalent in service provision and is one used by professionals. In the USA, *mental retardation* is still in common parlance. *Intellectual disability* is currently used by the academic literature and is likely to move into the provision and professional arena before long.

Intellectual disability is defined by ICD-10 (1996, p. 1) as:

...a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities.

People with intellectual disabilities have difficulties with learning and have global difficulties on a daily basis with living and coping skills. Like anybody else, people with intellectual disabilities have the potential to develop, but the rate at which this happens is likely to be slower and needs particular supports to be in place for it to happen.

A diagnosis of intellectual disability requires an assessment establishing that the individual meets three main criteria:

1. There is evidence of significant cognitive impairment, measured here as having an IQ of ≤ 70 .
2. There is also evidence that the individual has a significant impairment in adaptive functioning – assessed using standardised tools that measure everyday living and coping skills.
3. Both of these impairments are shown to have been present before the age of 18 years.

All three of these criteria must be met for a diagnosis of intellectual disability to be made.

Intellectual disability encompasses a very wide range of functioning, and this heterogeneity is perhaps one of the main difficulties faced by those responsible for developing service provision (see Chapter 18 for further discussion). ICD-10 also provides further categorisation within the diagnosis of cognitive impairment as shown in Table 1.1.

Causes of intellectual disability

Current thinking and research indicates that intellectual disability can be caused by biological, environmental and social factors. A view was held that mild intellectual

Table 1.1 Levels of cognitive impairment as described by ICD-10.

ICD code	Level of cognitive impairment	Associated IQ
F70	Mild	50–69
F71	Moderate	35–49
F72	Severe	20–34
F73	Profound	<20

disabilities were caused by social and environmental factors and severe and profound disabilities were caused by biological factors. However, evidence now exists to suggest that this distinction cannot be so clearly defined. For example, biological factors can now be shown to account for between one and two in five children with mild intellectual disabilities, as well as for four out of five children with severe intellectual disabilities (Fryers, 1993; Richardson & Koller, 1996).

Social and environmental factors

An early study by Birch et al. (1970) studied a cohort of children in Aberdeen identified as having intellectual disabilities and gathered a range of information via interviews and health and social care records. Their analysis found no relationship between severe intellectual disabilities and either the social class of the parents or family instability, but a strong relationship between parental social class and unstable family background (e.g. abuse, neglect or change of carers) and mild intellectual disabilities. This finding suggests that psychosocial adversity was a major factor contributing to mild intellectual disabilities but not to severe intellectual disabilities (Emerson et al., 2001).

Biological factors

Most of the biological causes of intellectual disabilities operate prenatally and in the majority of cases resulting in severe intellectual disabilities. Two-thirds to three-quarters of cases of severe intellectual disabilities are caused in this way, with the two most common genetic causes being Down's syndrome and Fragile-X syndrome. The most common non-genetic biological cause is cerebral palsy, although it is important to note that not all people with cerebral palsy have intellectual disabilities. Some biological factors can be effectively treated: for example, phenylketonuria is now screened in newborn babies using the heel-prick blood test, enabling treatment with thyroxine followed by a low-phenylalanine diet where indicated (Murphy et al., 1990). Others can be prevented via public health programmes, such as rubella immunisation to protect against pregnancies with rubella embryopathy.

Perinatal factors include birth trauma and cerebral hypoxia; post-natal factors include accidents and infections, such as meningitis.

Prevalence¹

According to Emerson & Hatton (2004), it is estimated that there are about 985 000 people in England with an intellectual disability (i.e. about 2% of the population), of which 796 000 are aged 20 or over.

¹ These figures are from the Foundation for People with Learning Disabilities, at www.learningdisabilities.org.uk.

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There are an estimated 210 000 people with severe and profound intellectual disabilities in England: around 65 000 children and young people, 120 000 adults of working age and 25 000 older people (Department of Health, 2001).

The number of adults with intellectual disabilities is predicted to increase by 11% between 2001 and 2021, raising the number of people in England aged 15 and above with intellectual disabilities to over one million in 2021 (Emerson & Hatton, 2004). The Department of Health (2001) suggests that this increase may be explained by:

- increased life expectancy, especially among people with Down's syndrome;
- growing numbers of children and young people with complex and multiple disabilities who now survive into adulthood;
- a sharp rise in the reported numbers of school age children with autistic spectrum disorders, some of whom will have intellectual disabilities;
- greater prevalence among some minority ethnic populations of South Asian origin.

About 60% of adults with intellectual disabilities live with their families (Department of Health, 2001) while about a third of all people with intellectual disabilities known to services live in care homes and hospitals. About 11 000 of these people live 'out of area', that is away from their home area (Department of Health, 2005).

Defining profound intellectual and multiple disabilities

While a clear, international consensus concerning the precise definition of PIMD is emerging², a range of definitions and descriptors have been published in recent times, the details of which can vary from each other. For example, while the World Health Organization (1993) equates profound intellectual disability with an IQ of below 30, the *Diagnostic and Statistical Manual* uses the range of 20–25 (*DSM-IV*; APA, 2000). Hogg & Sebba (1986) suggest that people with profound intellectual disabilities are functioning at five standard deviations below the norm, while Ware (1996) states that people forming this group of individuals have a degree of cognitive impairment so severe that they are functioning at a developmental level of 2 years or less. The World Health Organization (1996), in contrast, sets the criterion of functioning in adults at a level of below 3 years developmentally (see also Royal College of Psychiatrists 2001).

Clinical descriptions of PIMD

These slight variations in definition are academic in the main, although arguably such differences do serve to confuse and distract from the task in hand, that is to carry out thorough and holistic assessment (see Chapter 7). It is perhaps, therefore, easier to employ clinical descriptions of PIMD, which point one in the general

² See, for example, the work of the IASSID (International Association for the Scientific Study of Intellectual Disability) Special Interest Group at www.iassid.org.

direction as to how individuals functioning at this level might be affected by their various disabilities. For example, the World Health Organization (1996, p. 4) states that people in this range are likely to be:

...severely limited in their ability to understand or comply with requests or instructions. Most such individuals are immobile or severely restricted in mobility, incontinent, and capable at most of only the rudimentary forms of non-verbal communication.

It goes on to say:

They possess little or no ability to care for their own basic needs and require constant help and supervision.

DSM-IV-TR (APA, 2000, p. 44), in a similar vein, states that:

During the childhood years, they display considerable impairments in sensori-motor functioning... Optimal development may occur in a highly structured environment with constant aid and supervision and an individualised relationship with a caregiver. Motor development and self-care and communication may improve if appropriate training is provided. Some can perform simple tasks in closely supervised and sheltered settings.

Studies in the Netherlands have reported that at least 85% of people with PIMD have some form of visual impairment, in most cases caused by damage to the visual cortex in the occipital lobe (e.g. Van Splunder et al., 2003), and between 25 and 35% experience hearing loss (e.g. Evenhuis et al., 2001). Dysfunctions of taste and smell can be common (Bromley, 2000), along with impaired sense of touch, pressure, temperature and pain (e.g. Oberlander et al., 1999). Seizure disorders are reported to be 50% higher than that mentioned in the literature (e.g. Arts, 1999), and people with PIMD have a higher risk of developing medical complications (e.g. Zijlstra & Vlaskamp, 2005).

Without exception, these clinical descriptions take a deficit approach; in focusing on what individuals with PIMD are unable to do and the areas of life with which they have most difficulty, the reader is faced with a daunting list of problems and challenges. Indeed, the person is often noticeably absent. The medical model continues to be criticised for its diagnostic approach, and more recent thinking about the social construction of disability is often vehement in its condemnation of approaches that appear to consider people in terms of their perceived 'deviance' from social norms. Rapley (2004) reminds us that the word 'diagnosis' in talking about intellectual disability leads directly to a medicalisation of the individual. Rapley (2004, p. 43) refers to the work of Boyle (e.g. Boyle 1999) in summarising that:

...it has been by the appropriation of the language of medicine (with all of the supposed scientificity that goes with it ...) to talk of unwanted conduct that the psy professions [i.e. psychiatry and psychology] have assumed authority over the management and control of those who, in one way or another, trouble the social order.

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The debate concerning labelling, categorisation and the inevitable wielding of power that results from this process provides a tension between the call for clarity that enables discourse about need and a respectful acknowledgement of subjective perspective and dignity that we hope will be at least in part reflected by some of the contributors in this book. Our stance is to use language as the first step in establishing clarity, but as importantly to symbolically raise the profile of a population at risk of being at best ignored and at worst made to suffer through neglect. Throughout the chapters presented here, contributors use the term ‘profound intellectual and multiple disabilities’. In 2008, this has emerged as the most accurate way of describing a heterogeneous group of individuals who share the common experience of experiencing the world using skills that can be conceptualised as functioning at the very early stages of development in conjunction with both (usually a range of) additional physical and sensory disabilities and vulnerability to complex physical and mental health problems. Nakken & Vlaskamp (2007) have also championed this term, arguing for a clear definition of the ‘target group’ in order to prevent misunderstandings and improve dissemination of good practice. They observe that at an international congress in 2004, no fewer than 11 different terms were used to describe (apparently) similar groups of people in order to discuss treatment and support.

There is a view that the term ‘profound intellectual disabilities and multiple impairment’ is stigmatising a group of people that are already stigmatised enough. Perhaps as a way of avoiding this, *Valuing People* (Department of Health, 2001) made no specific reference to people with PIMD, instead using terms such as ‘complex needs’ and ‘high support needs’. This is arguably problematic as other groups within society – who do not have profound intellectual disabilities coupled with additional physical disabilities – could also be described using these terms. Examples include people experiencing significant and chronic mental health problems, such as treatment-resistant schizophrenia and other forms of psychotic illness, or people with a ‘dual diagnosis’ of mental illness and long-term substance misuse. Person-centred planning and person-centred action (see Chapter 6) place the individual at the centre of our thinking in order to identify what is going well in their life and then identify needs in order for these needs to be met. Lack of clarity – arguably aimed at making ourselves feel more comfortable with the language we are using – does not enable this process to unfold effectively.

Prevalence rates for people with PIMD

Figures for the population of people with PIMD understandably vary with the definition adopted. *DSM-IV-TR* (APA, 2000, p. 44) states:

... the group with profound mental retardation constitutes approximately 1–2% of people with mental retardation.

However, Cooper et al. (2007) worked with an adult intellectual disability population from which they identified 18% as having profound intellectual disabilities. This study used the ICD-10 criterion of functioning at ≤ 3 years in contrast to the *DSM-IV-TR* criterion (ICD-10, 1996).

Key areas in working with people with PIMD

This book takes a detailed approach to a range of issues pertinent to the lives of people with PIMD. These issues are underpinned or determined by a number of key areas as described briefly below.

Health

According to the Disability Rights Commission (2006), people with intellectual disabilities are 2.5 times more likely to have health problems than do other people, with 4 times as many people with intellectual disabilities dying of preventable causes as do people in the general population. This is clearly of concern when considering the evidence that people with PIMD are very likely to experience a wide range of complex health issues, often associated with particular conditions (e.g. issues with the digestive system linked with Cornelia de Lange syndrome and diseases of the nervous system seen in Angelman syndrome) and sometimes requiring significant intervention (Berg et al., 2007).

The development of better supports combined with advances in medical care means that the number of individuals with profound intellectual disabilities combined with fragile health is increasing in the developed world (Nakken & Vlaskamp, 2007). This increase brings with it the concept of 'older' people with PIMD; while there is increasing acknowledgement of the ageing nature of the wider intellectual disability population, there also needs to be recognition that people with PIMD are also reaching adulthood and beyond, with individuals now needing ever-increasing levels of complex technology to ensure that they not only survive, but do so enjoying an acceptable quality of life.

Capacity

The Mental Capacity Act (2005) and its consequent implementation in 2007 has enshrined the concept of capacity in law. It provides a statutory framework for substitute decision making for those who lack capacity, putting into statute common law principles and best practice. In excess of 2 million people in England and Wales lack capacity to make some decisions for themselves (Department for Constitutional Affairs, 2007). According to the Department for Constitutional Affairs (2007), there are 6 million carers and professionals who provide care and treatment, and prior to the Mental Capacity Act there had been no legal requirement for next of kin to be consulted with regard to treatment if their relative is not able to consent. Incapacity could be assumed on the basis of diagnosis alone and there was no clear legal authority for people acting on behalf of an individual without mental capacity. There had also been no statutory way for wishes regarding future care to be stated in advance and being certain that they are listened to.

The Mental Capacity Act has five main principles:

1. *Presumption of capacity.* A person must be assumed to have capacity unless it is established that he lacks capacity.

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2. *The right for individuals to be supported to make their own decisions.* A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
3. *The right to make 'unwise' decisions.* A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. *Best interests.* An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
5. *Least restrictive option.* Before the act is done, or the decision is made, regard must be paid to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Section 2(1) of the Act states that:

For the purposes of this Act, a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.

Capacity is assessed using a two-part test. Part 1 establishes whether there is an impairment of or disturbance in the functioning of the person's mind or brain. If that threshold is not reached (i.e. no impairment or disturbance is identified) the person cannot be seen to lack capacity within the Act. Part 2 of the test is a functional assessment which explores whether the impairment is sufficient that the person lacks the capacity to make that particular decision. Section 3 of the Act states that the person is then deemed unable to make that specific decision at that particular time if she or he is unable to:

- understand the information relevant to the decision;
- retain that information;
- use or weigh that information as part of the process of making the decision; or
- communicate the decision (talking, signing, other means).

The Act covers a range of decisions related to a person who lacks capacity in the areas of welfare (including health, medical and social care) and property and financial affairs. These can include everyday decisions or major choices (e.g. surgery and moving house). Many people with PIMD are likely to lack capacity, and the development of good practice in this area is essential.

Where an individual lacks capacity, a 'decision maker' needs to be identified whose task is to act in that individual's 'best interests' using the following checklist of considerations or principles:

- Take into account all relevant circumstances
- Encourage the person to participate as fully as possible
- Be aware of past and present wishes, feelings, beliefs and values

- Ensure inclusivity in relation to the views of carers, family members, the person named, local power of attorney or their deputy (if practicable and appropriate)
- Obtain written statements when the individual has capacity
- No discrimination
- Advocating for life-sustaining treatment, that is must *not* be motivated to bring about that person's death
- With regard to day-to-day decisions the person must have 'reasonable grounds for believing' that what they are doing is in the individual's best interest

The implementation of the Mental Capacity Act has a number of implications for clinicians. Clearly, they have a duty to comply with the Act and its Code, and rolling training programmes have been in place in many localities. There is likely to be an increase in demand for clinical psychologists and psychiatrists to carry out capacity assessments, with professionals from other health and social care disciplines requesting consultancy and training in this important area.

Integration of health and social care services

The stance adopted in the following chapters together strive towards a 'both/and' position rather than 'either/or'. For the contributors in this volume, medical interventions and good, effective healthcare in general matter just as much as the acknowledgement of personhood and autonomy. Emotional well-being and positive emphasis on achievement and attainment are just as important as thorough assessment of dysphagia, respiration and postural management. At risk of stating what is clearly apparent, all of these issues are interdependent. Artificial positioning of the social model as being diametrically opposed to the medical model is thankfully outdated when applied to the lives of people with mild or moderate intellectual disabilities; however, it can be the case that when support for people with PIMD is being considered the integration of health and social care becomes more difficult. Local implementation can lead to intervention being primarily about providing clinical input to address identified health concerns to the detriment of considerations about rights and quality of life, *or* such medical issues are hidden beneath the drive towards ensuring that the individual concerned is living an 'ordinary' lifestyle, compromising risk management and appropriate healthcare provision.

The chapters in this book attempt to thoroughly investigate the issues and appropriate related interventions across all areas of functioning for people with PIMD and are organized into two main sections which explore the assessment and meeting of complex needs respectively. The first section begins by mapping the main areas that enable the development of a positive perspective on the lives of people with PIMD. Katja Petry and Bea Maes begin by discussing the concept of quality of life and its application to people with PIMD, an essential starting point for considering what people need and why support is offered in the ways recommended in later chapters. Jan Roast and colleagues extend this by sharing their own stories, grounding these ideas in real life and practical experiences.

The next three chapters together form the core foundation of thinking that underpins the best practice set out in Section 2. Karen Bunning emphasises the essential role of communication partnerships, providing clear and helpful guidance on developing an understanding of the ways in which communication skills can be supported and enhanced. Melanie Nind builds on these ideas in discussing the importance of emotional well-being, arguably an area that has been largely ignored until relatively recently and here taking its rightful place at the very centre of best practice. The third core element, supporting the attainment and maintenance of good health, is discussed in the context of meaningful, person-centred and personally relevant planning of effective healthcare driven by acknowledgement and implementation of appropriate policy and guidance. The final chapter in this section attempts to draw the ideas discussed thus far in highlighting the need for thorough transdisciplinary, rather than merely multidisciplinary, assessment.

With the wider context and value base now established, Section 2 takes a 'head to toe' approach to meeting complex needs, with contributors focusing on key areas and suggesting best practice. Mental health issues for people with PIMD have been largely underresearched, and the first chapter in this section reviews what is reported to be understood about this difficult area at the present time. Mary Codling and Nicky MacDonald then go on to discuss epilepsy, providing a full account likely to be essential reading for practitioners. Sensory loss is discussed firstly by Gill Levy in her chapter on vision and visual impairment and then by Laura Waite's chapter on hearing loss.

Respiratory health is reviewed by Colin Wallis, who provides invaluable information that is both illuminating and reassuring in its practical, measured approach. Similarly, Pauline Watt-Smith's discussion of dental care and oral health emphasises the need for proactive approaches that recognise the essential adoption of specific practices for people with such significant disabilities, as do the chapters by Hannah Crawford on dysphagia and by Sian Burton and colleagues on nutrition, hydration and weight, respectively. Sarah Hill and Liz Goldsmith conclude Section 2 with a detailed and accessible account of good postural management.

Meeting Complex Needs concludes with a review of the themes and arguments raised throughout the book, revisiting some of the discussion set out in this introduction and proposing an agenda for further development of service provision. In doing so, it attempts to join all of its contributors in raising the hidden profile of a group of individuals who in twenty-first-century society are still shamefully at risk of being ignored.

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